

Post-Treatment Follow-up Care for Cancer Survivors – Why Is It Important?

Noreen M. Aziz MD, PhD, MPH

Program Director

Office of Cancer Survivorship

National Cancer Institute

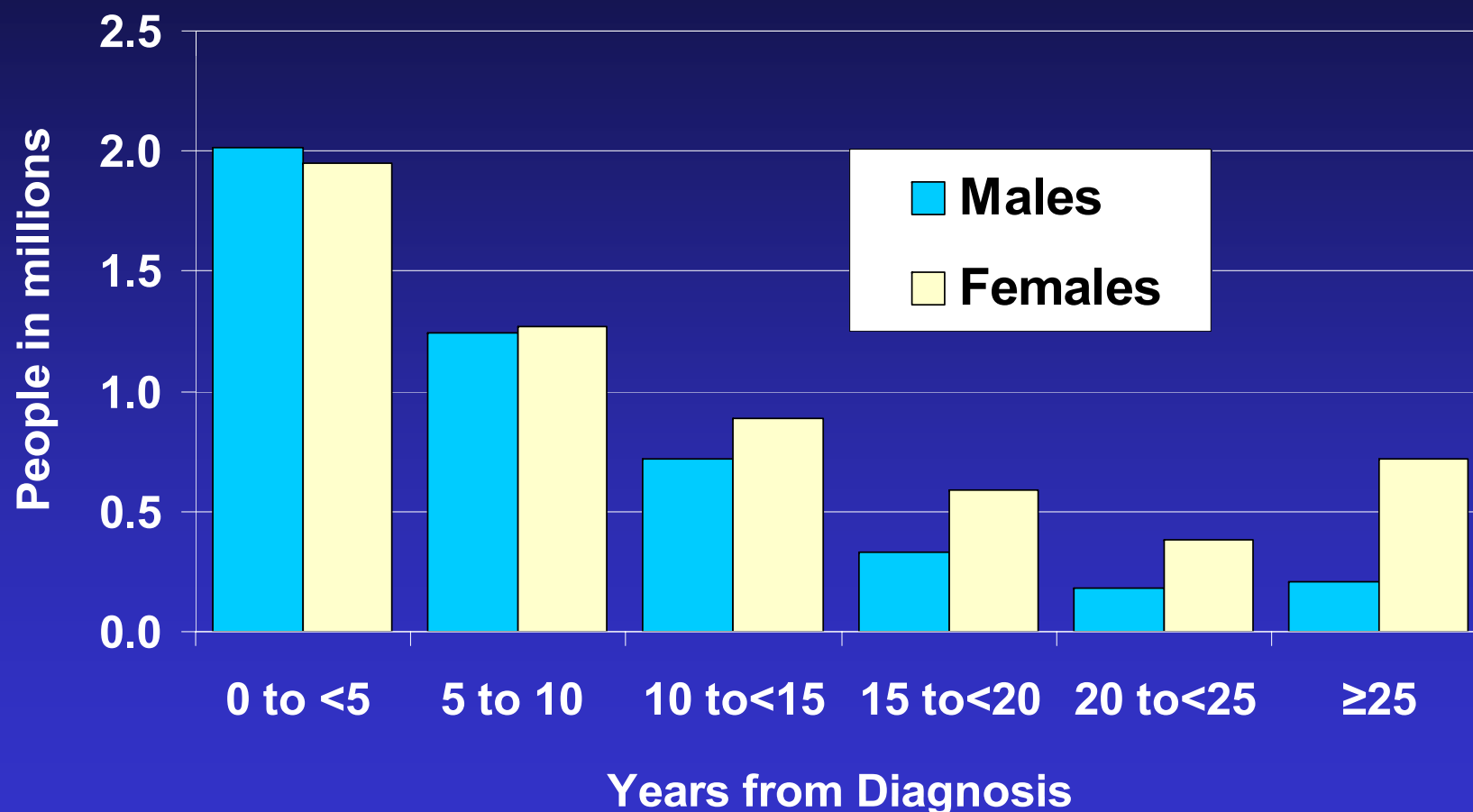
October 5, 2006

Current Number of Cancer Survivors

- It is currently estimated that there are 10.5 million cancer survivors in the United States, representing approx. 3.5 % of the population.
- Worldwide, current prevalence estimates range from 20 to 24 million!



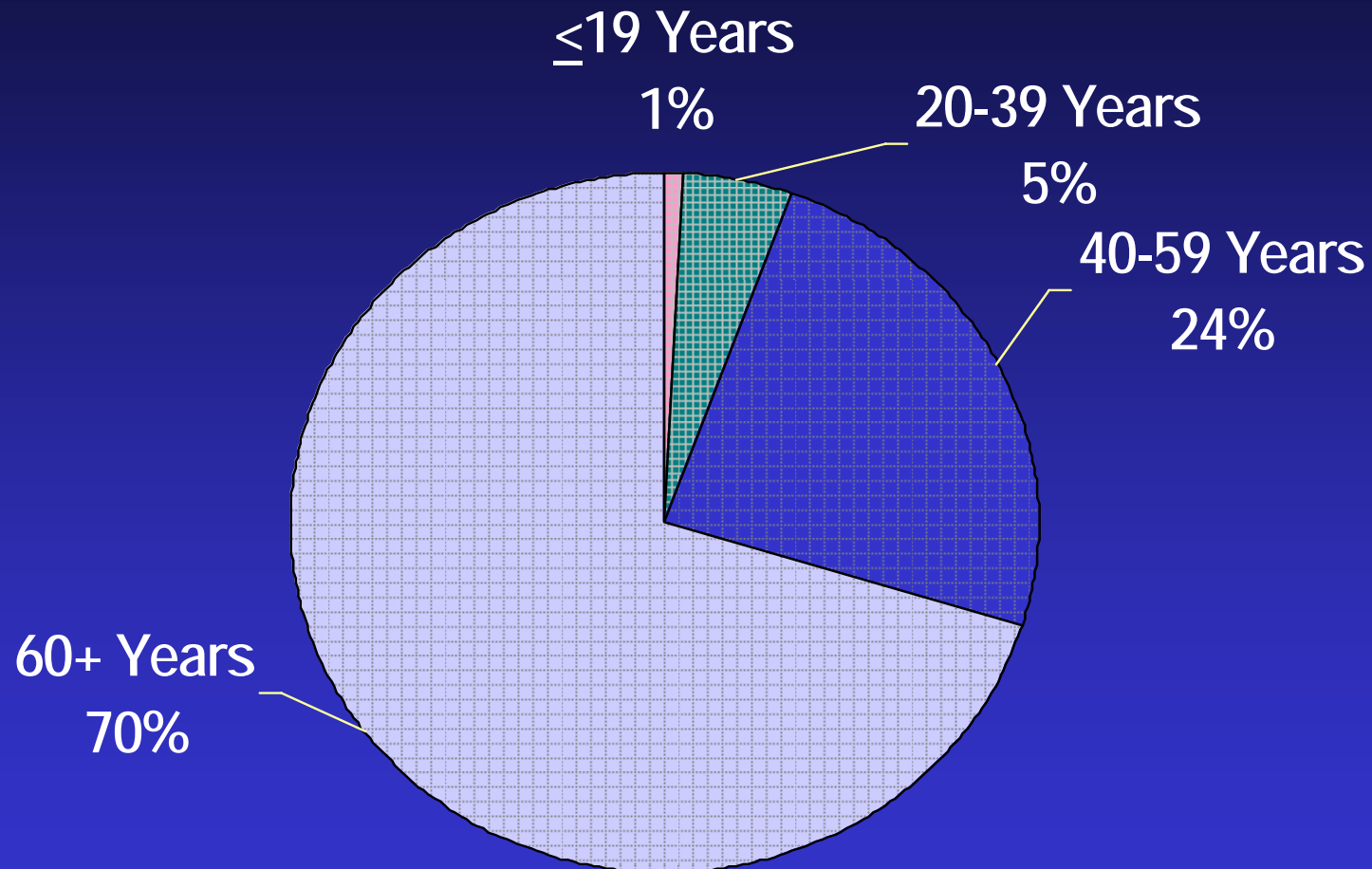
Estimated Number of Persons Alive in the U.S. Diagnosed with Cancer on January 1, 2003 by Time From Diagnosis and Gender (Invasive/1st Primary Cases Only, N = 10.5M survivors)



Data source: 2005 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2003 were based on the average of the July 2002 and July 2003 population estimates from the U.S. Bureau of Census.

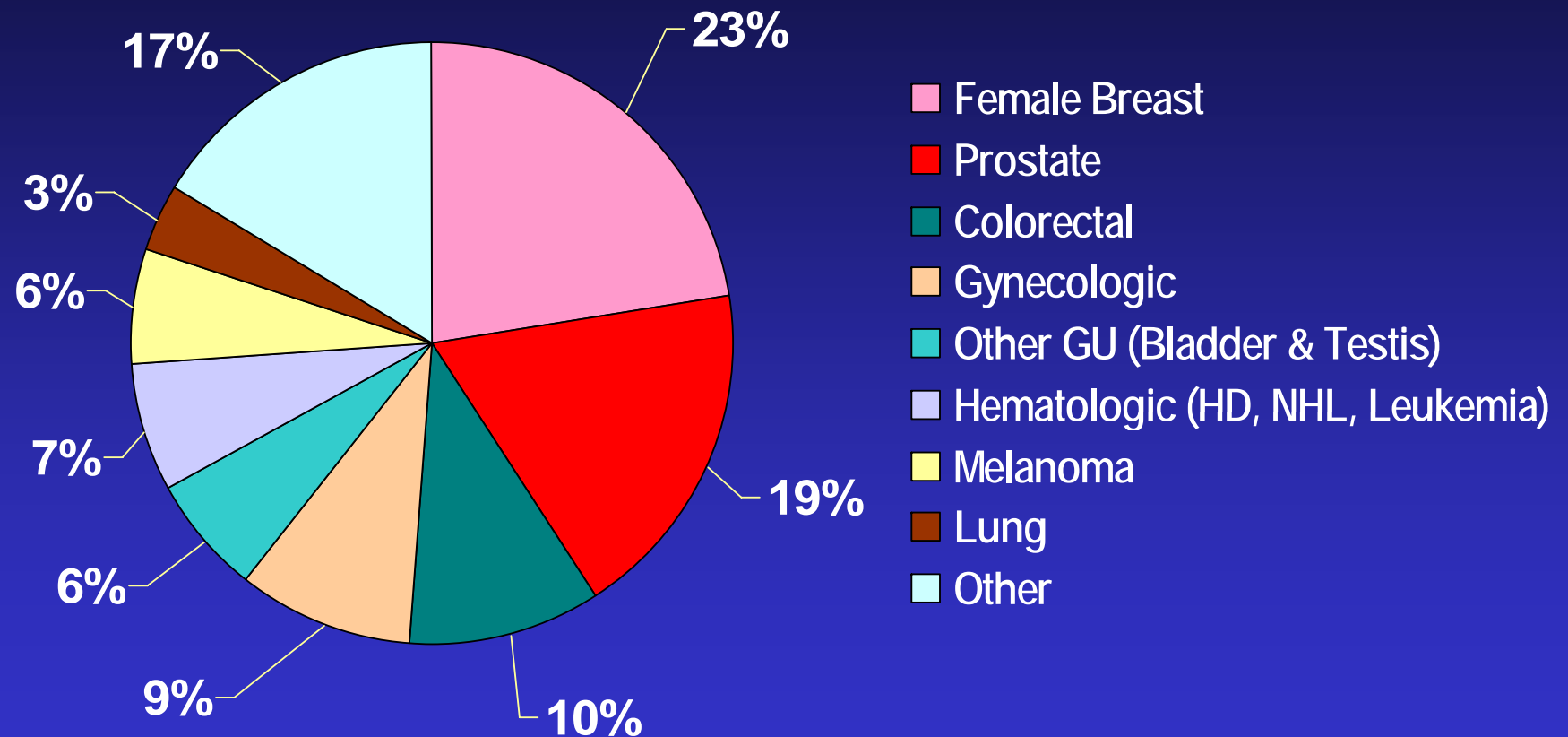
Estimated Number of Persons Alive in the U.S. Diagnosed With Cancer by Current Age*

*(Invasive/1st Primary Cases Only, N=10.5M survivors)



Data source: 2005 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2003 were based on the average of the July 2002 and July 2003 population estimates from the U.S. Bureau of Census.

Estimated Number of Persons Alive in the U.S. Diagnosed With Cancer by Site (N = 10.5 M)



Data source: 2005 Submission. U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 and historical Connecticut Limited Duration Prevalence proportions and adjusted to represent complete prevalence. Populations from January 2003 were based on the average of the July 2002 and July 2003 population estimates from the U.S. Bureau of Census.

Background

- The population of cancer survivors continues to grow: 64% of adult and 79% of pediatric cancer survivors survive beyond 5 years. Cancer can be, for most, a chronic disease.
- Most current cancer therapies (surgery, chemotherapy, radiotherapy) are known to carry substantial risk of adverse long-term (chronic / persistent) or late treatment related effects (occurring months to years after cancer treatment has ended).
- The sizeable and growing population of cancer survivors presents significant questions related to treatment decisions, the impact of medical effects of cancer treatment on health and quality of life, and long-term follow-up care needs (related to cancer *and* other chronic comorbid conditions).



Background

- It is critical, if we are to develop effective research priorities and recommendations for clinical care, education, and policy related to care for survivors of cancer, that we note points:
 - ▶ the population of cancer survivors consists of individuals with varying needs and issues - those cured of their disease and no longer undergoing active treatment, as well as patients with recurrences or resistant disease requiring ongoing treatment; and
 - ▶ regardless of disease status, any survivor may experience lasting adverse effects of treatment. [Yabroff KR, et al. Burden of illness in cancer survivors: findings from a population-based national sample J Natl Cancer Inst 2004;96\(17\):1322-30.](#)
 - ▶ Follow-Up Care for Cancer Survivors is highly complex in nature!!



Background

- Goal of Survivorship Research:
 - ▶ Reduce the adverse effects of cancer diagnosis and treatment, and optimize outcomes for cancer survivors and their families
 - ▶ Major emphasis: Examination of post-treatment follow-up care of individuals diagnosed with cancer, and the development and dissemination of best practices for follow-up care, surveillance, and monitoring of the ever growing population of cancer survivors



Background

- Several Institute of Medicine (IOM) reports, Progress Review Group (PRG) documents, and NCI bypass budgets call for research that will increase length and quality of life for those diagnosed with and treated for cancer .
 - ▶ Continued medical follow-up of survivors should include basic standards of care that address the specific needs of long-term survivors.
 - ▶ The IOM Report on cancer survivors diagnosed as adults articulates key areas for research and care delivery, eg. the development of a formal care plan that integrates, within one document, key treatment relevant variables, exposures, late effect risks, and management / follow-up care needs.



Background

- ▶ The IOM report on childhood survivorship cites the need to create and evaluate standards and alternative models of care delivery, including collaborative practices between pediatric oncologists and primary care physicians as well as hospital-based long-term follow-up clinics.
- Despite their potential health limiting impact, the medical sequelae of cancer and its treatment, *and the follow-up care practices relevant to anticipating or managing these, remain poorly documented or understood.*

From Cancer Patient to Cancer Survivor: Lost in Transition. Hewitt M, Greenfield S, and Stovall E, eds. National Academies Press, Washington D.C., 2005.

Childhood Cancer Survivorship: Improving Care and Quality of Life. Hewitt M, Weiner S, and Simone J, eds. National Academies Press Washington D.C. 2003



Survivorship Research and Optimal Post-Treatment Follow-Up Care: *The Interface*

- The essential ultimate goal of cancer survivorship research is the reduction of adverse effects of cancer diagnosis and treatment, and the optimization of outcomes for cancer survivors and their families
- It is, therefore, imperative that we study the inter-relationships between chronic and late sequelae of cancer treatment and the provision of quality care for cancer survivors



Sequelae of Cancer Treatment

- Physiologic
- Psychosocial
- Economic
- Multifaceted and inter-related nature of sequelae
- Issues are *not* extensions of the cancer patient in treatment
- Diversity of Sequelae: Physical / Physiologic - Societal / Interpersonal



Late Effects of Cancer Treatment

- Physical/Medical (e.g., second cancers, cardiac dysfunction, pain, lymphedema, sexual impairment)
- Psychological (e.g., Depression, anxiety, uncertainty, isolation, altered body image)
- Social (e.g., changes in interpersonal relationships, concerns regarding health or life insurance, job lock/loss, return to school, financial burden)
- Existential and Spiritual Issues (e.g., Sense of purpose or meaning, appreciation of life)



Goals of Follow-Up Care*

- Prevent premature mortality
- Prevent or detect early physiologic or psychosocial sources of morbidity
- Manage (or refer for management of) co-morbidities
- Screen for 2nd cancers
- Appropriate and timely referral to specialists for optimal management of adverse outcomes, co-morbidities, screening for 2nd cancers / recurrence, and other chronic conditions
 - ▶ Ongoing monitoring and assessment is necessary to accomplish these goals
 - ▶ Are these goals implicit in nature? Have they been articulated *a priori* by practitioners and programs?

* In addition to routine care, annual physicals, etc



Follow-Up Care Research

What are we learning from ongoing studies?

What are some interesting research findings that point us towards future directions in this new area?



Research Findings

Follow-Up Care

- Long-term adverse outcomes are more prevalent, serious, and persistent than expected.
- Late effects of cancer and its treatment in survivors, especially among those diagnosed as adults, and / or those belonging to ethno culturally diverse or medically underserved groups, remain poorly documented.
- Survivors of cancer have significantly poorer health outcomes on multiple burden-of-illness measures than do people without a history of cancer.
 - ▶ These health decrements may occur or continue many years after diagnosis.

Earle CC, Neville BA. Under use of necessary care among cancer survivors. *Cancer* 2004;101(8):1712-9.



Research Findings

Follow-Up Care

- Co morbid conditions are another major issue for many diagnosed with cancer, yet little is known about the quality of the non-cancer-related care receive by these survivors.
Deimling GT, et al. Cancer survivorship and psychological distress in later life. [Psychooncology](#) 2002;11(6):479-94.
- Compared with matched controls with no history of cancer, it has been reported that it is more likely that survivors would not receive recommended care across a broad range of chronic medical conditions (e.g., angina, congestive heart failure, and diabetes).
- Quality-of-life issues in long-term survivors of cancer differ from the problems they face at the time of diagnosis and treatment. *Ferrell BR, Hassey Dow K. Quality of life among long-term cancer survivors. [Oncology \(Williston Park\)](#) 1997;11(4):565-8, 71; discussion 72, 75-6.*



Research Findings

Follow-Up Care

- Very few long-term survivors of childhood cancer (28%) undertook a cancer-related follow-up care visit in the previous 24 months in a US study
 - ▶ When asked about the likelihood of a check-up for cancer-related health problems over the next 2 years, the following results are illustrative: V. unlikely 22%; Unlikely 19%; Possibly 18%; Likely 12% Very likely 29% [Oeffinger et al. 2004](#)



Research Findings

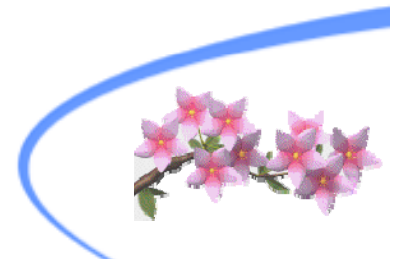
Follow-Up Care

- While 34% of survivors reported having seen a primary care provider for *problems related to their previous cancer*, the following intriguing responses were also obtained:
 - ▶ 65% felt that a primary care provider could only sometimes (34%), not very often (21%), or almost never (10%) handle problems related to cancer or its treatment
 - ▶ Only 35% felt that primary care providers could almost always (14%) or very often (21%) handle problems related to cancer
- Survivors fears and concerns included:
 - ▶ Uncertainty about future health (24%)
 - ▶ Worry about cancer coming back (14%)
 - ▶ Wanting to forget the cancer (25%)
 - ▶ Worry about being a “hypochondriac” (8%)
 - ▶ Worry about problem being discovered with a check-up (14%) ([Oeffinger et al. 2004](#))



Survivorship and Long-Term Follow-Up Care: *Implications of Research Findings*

- Post-treatment follow-up care has the potential to affect the health and life of all individuals diagnosed with cancer
- There is perhaps no other issue during survivorship that assumes such a level of importance both in survivors' lives and in providers' goals for optimal management
- Follow-up care after cancer is truly a lifelong partnership between survivors, their families, and their providers



Acknowledged Issues in the Provision of Quality Follow-Up Care

- Cancer Survivors need significant follow-up care and monitoring for the balance of their lives.
- The frequency and intensity of follow-up care diminishes with each year after the completion of treatment, with dramatic fall-off 2-5 years post-treatment. Conversely, the risk of late effects and the impact of long-term effects *increases* with the passage of time.
- Not all survivors or their providers, especially those who are primary care practitioners, may be aware of the late effects for which individuals treated for cancer may be at risk.
- There is a lack of, and significant need for, population-based data on quality of follow-up care and health outcomes in this critical part of the cancer continuum



Acknowledged Issues in the Provision of Quality Follow-Up Care

- Optimal Follow-Up of Cancer Survivors requires:
 - ▶ Ongoing Monitoring and Assessment
 - ▶ Appropriate interventions to ameliorate adverse sequelae
- The Challenge and Opportunity underlying these goals:
 - ▶ The prevention of premature mortality and unnecessary, preventable morbidity
 - ▶ The prevention or early detection of physiologic and psychologic sources of morbidity



Questions and Issues Regarding the Provision of Quality Follow-Up Care

- *Who is monitoring survivors for late effects and adverse sequelae?*
- *What is the optimal setting for post-treatment follow-up care?*
- *How should we prepare survivors for late effects and adverse sequelae?*
- *How can we increase scientific knowledge about adverse sequelae of treatment?*
- *What can we accomplish through the conduct of research that addresses follow-up care and related issues among cancer survivors?*
- *What can we accomplish through integrated efforts from follow-up care centers or follow-up care research consortia?*



Who Is Currently Monitoring Cancer Survivors for Adverse Late Effects?

- Interdisciplinary and Integrated vs. fragmented vs. single discipline
 - ▶ Role of Oncology Specialists
 - ▶ Role of Primary Care Physicians
 - ▶ Role of Nurses
 - ▶ Role of Psychologists, Social Workers, Physiotherapists
 - ▶ Role of survivors themselves
- Should there be specialized Survivor Clinics in hospitals or cancer centers? Should be clinic consortia? Who should be staffing these clinics, consortia, or centres?



How Should We Prepare Survivors for Potential Late Effects?

- Provide survivors with information about their treatment and its late effects
 - ▶ Role of a comprehensive discharge summary
- Openly discuss the need for long-term follow-up
- Encourage their participation in research studies when available
- Examine late and long-term effects of cancer treatment systematically and rigorously



How Might We Increase Scientific Knowledge Regarding Late Effects of Cancer Treatment?

- Conduct systematic research
- Efficient use of the cooperative groups and cancer registries
- Examine and compare optimal models of follow-up care delivery
- Evaluate the impact of survivor clinics, registries, consortia with research funding for medical and psychosocial evaluations, utilizing measurable goals?



What Can We Accomplish through the Conduct of Follow-Up Care Research?

- *Define* the frequency, content, optimal settings for, and ideal providers of, post-treatment follow-up care.
- *Develop* best practice guidelines for follow-up of cancer survivors
- *Evaluate* existing programs that provide follow-up care for cancer survivors?
 - ▶ Are they effective?
 - ▶ Are they achieving program goals?
 - ▶ Have program goals been clearly articulated? Are they testable?
 - ▶ Are they tied to survivors' health outcomes?
 - ▶ Have survivor perspectives been addressed / incorporated?



What Can We Accomplish Through Integrated Efforts at Follow-up Care Centers / Consortia?

- *Define* what integrated efforts at follow-up centers / consortia would entail
 - ▶ A group of individuals with a common goal?
 - ▶ What is that common goal?
 - Research (interventions to ameliorate late effects)
 - Clinical (long-term follow-up for late effects)
 - Definition and implementation of standards of follow-up care?
- *Identify* major questions / key foci in post-treatment follow-up care of cancer survivors (e.g. Models of care; Evidence based guidelines; Program evaluation)
- *Delineate* testable outcomes / end-points (patient driven or system driven) relevant to follow-up care research



What Can We Accomplish Through Integrated Efforts at Follow-up Care Centers / Consortia?

- *Synthesize* issues in key areas, develop recommendations that address identified gaps and needs;
- *Develop* evidence based best practice guidelines for follow-up of cancer survivors
- *Validate* these standards and guidelines
- *Conduct* retrospective, and later, prospective evaluative research
- *Develop, Define, and Test* Models of Care
- *Lead efforts to lay the foundations for* follow-up care of cancer survivors as an evidence based science



Research Questions Relevant to Cancer-Related Follow-up Care

- Examine the frequency, content, optimal setting and optimal providers (cancer center, specialized programs, or community practice) of follow-up care received by the broader population of cancer survivors.
 - ▶ Test strategies / methods through which quality of care for cancer survivors, as they progress through the survivorship continuum, can be improved.
- Utilize this understanding to develop standards for follow-up care of survivors *with a view towards preventing, detecting early, or ameliorating long-term or late effects of cancer and its treatment.*
- Evaluate existing follow-up care programs / strategies
- Develop and test best practice guidelines and optimal models of follow-up care based on primary cancer site, age, etc



Research Questions Relevant to Cancer-Related Follow-up Care

- Elucidate:

- ▶ What is Quality of Care?
- ▶ What are the barriers to care?
- ▶ Whether we are providing quality care across diverse ethnocultural, income, age, and geographical settings?
- ▶ Whether and how we can achieve equity?



Defining Quality Cancer-Related Follow-up Care – *How do we know where to begin?*

Integrate our efforts: The sum of the parts is greater than the individual components

Develop and test Models / Paradigms Relevant to Post-Treatment Cancer-Related Follow-up Care

Be cognizant of a paradigm Shift: from a focus solely on cure towards a goal that maximizes cure and minimizes the risk of adverse late or long-term consequences of cancer and its treatment (the cost)

